

End of Life Care Manual



A Program Guide for Washington Hospitals

Legal Requirements and General Guidance for Addressing End of Life Care in the Context of Advance Directives, Surrogate Decision-Making and Organ Procurement.

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Association of Washington Public Hospital Districts

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Resources

Information for Patients and Families

If you are a patient or family member looking for resources to help in your medical decision-making, Honoring Choices Pacific Northwest is designed for you. Co-sponsored by the Washington State Hospital Association (WSHA) and Washington State Medical Association (WSMA), Honoring Choices has a vision that everyone in the state will receive medical care that honors their personal values and goals. Learn more at [Honoring Choices](#).



Introduction

Welcome to the 2008-2009 End of Life Care Manual. This manual contains materials to assist health care facilities, particularly hospitals, to meet the legal requirements regarding advance directives, surrogate decision-making, and organ procurement. The 2008-2009 edition of the End of Life Care Manual updates and expands the information provided in the 2001 edition. This updated version includes a new section on mental health advance directives and an expanded section on the Physician Orders for Life-Sustaining Treatment (POLST) Program.

Section One addresses federal and state law on advance directives. The section includes information on the Patient Self-Determination Act, Medicare Conditions of Participation for hospitals and long-term care facilities, and the Joint Commission standards on advance directives, end-of-life care, and surrogate decision-making. Washington state regulations specific to nursing homes are also summarized in Section One.

Section Two focuses on Washington state's mental health advance directive law. In addition to an overview of the legal obligations of hospitals, this section contains a list of additional resources, a model hospital policy, clinician's checklist, patient brochure, and sample mental health advance directive.

Section Three contains the text of the law discussed in Sections One and Two.

Section Four of this manual includes guidelines for developing hospital policies and procedures, creating patient information materials, and educating the community about advance directives. This information is intended to assist hospitals in meeting the requirements of the law discussed in Section One. A sample brochure on advance directives is provided at the end of this section.

Section Five addresses the law on surrogate decision-making. It focuses on the steps hospitals must take to comply with state law, Medicare Conditions of Participation, and Joint Commission standards. The texts of relevant state statutes and regulations are included.

Section Six contains information on the Physician Orders for Life-Sustaining Treatment (POLST) program. In addition to an overview of POLST, the section includes a list of resources, a POLST form, an example of DSHS approved policy and procedure guidelines for nursing homes, sample procedures for POLST intake, sample guidelines for nurses, and a patient brochure.

Section Seven describes hospital obligations regarding organ procurement, in particular Washington State's new law concerning organ donation. The organ procurement section also includes a list of resources and a resource guide produced by the U.S. Department of Health & Human Services.

The last section is a **Resource Section**. The resources listed provide guidance for providers and patients faced with end-of-life decisions. The organizations listed provide information on end-of-life care, both general and specific. The providers' resource page includes information pertaining specifically to best practices for the provision of palliative care. General information on advance directives can also be obtained from many of these organizations.

This guide is intended to inform hospitals of their legal responsibilities in relation to end-of-life care. The information presented is current as of September 2008. Please consult an attorney with specific questions or concerns.

Section 1: Advanced Directives Law

The federal Patient Self-Determination Act (PSDA), enacted in 1991, dictates that health care institutions certified by Medicare and/or Medicaid must take steps to educate all adult patients and the larger community on their right to accept or refuse medical care.⁽¹⁾ This law also directs facilities to inquire on admission whether a patient has made an advance directive, maintain policies and procedures on advance directives, and provide this information to patients upon admission. Organizations must comply with the PSDA in order to receive reimbursement through the Medicare and Medicaid programs. (The federal and state regulations implementing the Patient Self-Determination Act, along with the relevant state statutes and regulations mentioned in this section, can be found in Section Three.)

Specifically, the PSDA requires providers to inform patients of their rights, under state law, to make decisions about their medical care and the right to formulate advance directives. The PSDA defines an advance directive as a, “written instrument, such as a living will or durable power of attorney for health care, recognized under state law? relating to the provision of such care when the individual is incapacitated.” ⁽²⁾

In Washington State, an individual’s right to control decisions involving their health care and to make an advance directive is codified in two places:

1. An individual’s right to control decisions involving health care via an advance directive is codified in the Natural Death Act in chapter 70.122 of the Revised Code of Washington.⁽³⁾
2. An individual’s right to control decisions involving mental health care by making a mental health advance directive is codified in chapter 71.32 RCW, concerning mental health advance directives.⁽⁴⁾

Both types of advance directives fit the definition in the PSDA as written instruments, recognized under state law, relating to the provision of care when the individual is incapacitated.

To ensure compliance with the PSDA, hospitals, including rural primary care hospitals, nursing facilities, providers of home health care, health maintenance organizations, competitive medical plans, and hospice programs certified by Medicare and/or Medicaid must:

- maintain written policies and procedures on advance directives with respect to all adult individuals receiving medical care by or through the provider or organization;
- provide written information to each such individual concerning the individual’s rights under state law (whether statutory or recognized by the state’s courts) to make decisions concerning medical care including: the right to accept or refuse medical or surgical treatment, the right to formulate advance directives, and the hospital’s policies respecting the implementation of such rights;
- document in the individual’s medical record whether or not the person has executed an advance directive;
- not condition the provision of care or otherwise discriminate against an individual based upon whether or not the individual has executed an advance directive;

- ensure their written policies on advance directives include a clear and precise statement of limitation if the provider cannot implement an advance directive based on moral or ethical objections, including the legal authority for such objection (see the Natural Death Act or the Mental Health Advance Directive chapter) and whether the objection is institution-wide or may be raised by an individual provider;
- inform individuals that complaints concerning the advance directives requirements may be filed with the state survey and certification agency;
- ensure that the facility complies with state law concerning advance directives (see the Natural Death Act and the Mental Health Advance Directive chapter);
- educate staff on the facility's policies and procedures concerning advance directives; and
- provide for community education. The educational materials must inform the public of their rights under state law to make decisions about their medical care, the right to formulate advance directives, and the facility's implementation policies concerning an individual's advance directive.

The written information concerning advance directives must be provided to an adult individual by:

- hospitals, at the time of inpatient admission;
- nursing facilities, at the time of admission;
- home health care or personal care services, in advance of the individual coming under the care of the provider;
- hospices, at the time of initial receipt of hospice care; and
- HMOs, at the time of enrollment.

If an individual is incapacitated at the time of admission or is otherwise unable to articulate whether or not he or she has executed an advance directive, information about advance directives may be given to an individual's family or surrogate.

Questions & Answers Regarding the Patient Self-Determination Act (PSDA)

(The information below has been extracted from the comment and answer section of the PSDA regulations.)

Q: If an individual is admitted to the hospital incapacitated, must the hospital meet the PSDA requirement that it give each individual admitted to the hospital written information about advance directives?

A: If an individual is incapacitated at the time of admission and is unable to receive information or articulate whether or not she or he has an advance directive, the facility should give advance directive information to the patient's family or surrogate to the extent that it gives other materials about policies and procedures to an incapacitated person's family, surrogate, or other concerned person in compliance with state law.

Q: When an individual is first admitted as an inpatient to a hospital and later transferred to a nursing home, are both facilities responsible for providing information on advance directives to the individual?

A: Yes, both the hospital and the nursing home would be required to provide information on advance directives to the individual. The hospital discharge planner may provide the information on behalf of the nursing home, including the nursing home's policies regarding advance directives, in the course of coordinating the transfer, but the nursing home would still be responsible for ensuring the individual received the information and to mark in the individual's medical record whether or not she or he has an advance directive.

Q: Are individuals required to execute an advance directive?

A: No. In fact, the PSDA specifically prohibits providers from conditioning care on whether or not an individual has executed an advance directive. The regulations make clear that the PSDA's main intent is to ensure patients receive information about the right to accept or refuse medical or surgical treatment and about the right to formulate an advance directive.

Q: What constitutes minimally sufficient educational efforts in meeting the PSDA's community education requirements?

A: The PSDA allows great flexibility in the level of community education it requires. At a minimum, a provider must be able to document its community education efforts. For example, photocopying a brochure or pamphlet that meets the community education requirements and was distributed to the public may be sufficient to show the community education requirement was met. Community education does not necessarily require the distribution of written materials and may be carried out in a variety of formats at the provider's discretion (workshops, seminars, etc.).

Q: May a provider exempt itself from the community education requirement based on conscience?

A: No. A provider must meet its obligation to provide community education on advance directives. Under state law, a provider may conscientiously object to implementing an advance directive. However, a provider's conscientious objection must be included in the provider's policy and mentioned in both its community education materials and the materials distributed to individuals upon their admission to the facility.

The Washington State Living Will Registry

In 2006 the legislature passed a statute directing the Department of Health to establish and maintain a statewide online health care declarations registry.⁽⁵⁾ A person can upload directives onto a secure website and these directives will then be accessible to patients, personal representatives, and health care providers. Individuals may submit a health care directive, durable power of attorney for health care, mental health advance directive, or a POLST form.⁽⁶⁾ The Department of Health's website for the registry is located at <http://www.doh.wa.gov/livingwill>. A power point presentation for hospitals describing the website and how it works can be found at: [WSHA Webcasts](#).

Submitting or failing to submit a directive to the registry does not affect the validity of the directive, alter the laws regarding the requirements necessary to make a document legal, or create a presumption

regarding the validity of the document.(7) Revocation of a directive stored in the registry must conform to the standard statutory method. Failure to notify the Department of Health of a valid revocation does not affect the validity of the revocation.(8)

According the enacting legislation, the legislature intends the registry be consulted by providers in instances where there may be a question about the patient's wishes and the existence of an advance directive might clarify the patient's intentions. The registry does not create any new or distinct obligations for a provider or facility to ascertain the existence of a directive.(9) A provider is not subject to criminal or civil liability or sanctions for unprofessional conduct if the provider provides, does not provide, withdraws, or withholds treatment:

- to a patient in the absence of actual knowledge of the existence of a health care declaration stored on the health care declarations registry;
- pursuant to a health care declaration stored in the registry in the absence of actual knowledge of the revocation of the declaration;
- according to a health care declaration stored in the registry in good faith reliance upon the validity of the declaration that is subsequently found to be invalid; or
- according to a patient's health care declaration stored in the registry.(10)

Medicare and Medicaid Conditions of Participation

Hospitals

Medicare and Medicaid Conditions of Participation for hospitals are the minimum requirements that hospitals must meet to participate in the Medicare and Medicaid programs. Conditions of Participation are intended to protect patient health and safety and to assure that high quality care is provided.

These requirements apply to all Medicare or Medicaid participating hospitals. This includes: short-term, acute care, surgical, specialty, psychiatric, rehabilitation, long-term, children's, and alcohol/drug treatment facilities, whether or not they are accredited. This rule does not apply to Critical Access Hospitals (see Social Security Act Section 1861(e)). Critical Access Hospitals and long-term care facilities are addressed later in this section.

The Conditions of Participation for advance directives have been in effect since 1991 and are largely a product of the Patient Self-Determination Act (PSDA). Therefore, their requirements mirror those of the PSDA outlined in the Federal and State Law on Advance Directives portion above and will not be duplicated here.(11)

In 1999 an interim final rule, called the "Patients' Rights" Conditions of Participation for hospitals, became effective.(12) The Conditions of Participation for patients' rights address hospitals' obligations regarding advance directives and end-of-life care. The Centers for Medicare and Medicaid Services (CMS) finalized changes to the Conditions of Participation for Patients' Rights standards in January 2007. The sections pertaining to advance directives, end-of-life care, and right to participation in treatment decisions are unaltered from the 1999 language.

The Conditions of Participation for Patients' Rights relevant to end-of-life care and advance directives state that:

- patients have the right to participate in the development and implementation of their plan of care;
- patients (or their representatives under state law) have the right to make informed decisions regarding their care, know their health status, be involved in their care planning and treatment, and be able to refuse or request treatments;
- patients have the right to formulate advance directives and to have hospital staff and practitioners comply with these directives (in accordance with the conditions of participation on advance directives).(13)

The CMS issued interpretive guidelines regarding the Conditions of Participation for Patients' Rights.(14) These guidelines stress that, whenever possible, the hospital should inform a patient of her or his rights in a language the patient understands. The interpretive guidelines also state that hospitals must be sensitive to the communication needs of its patients. Hospitals must also comply with Civil Rights laws that ensure it will provide alternative communication techniques or aides for those who are deaf or blind, or take other steps as needed to effectively communicate with the patient. To comply with these guidelines hospitals may need to use large print materials, specialized programs to inform those who are deaf or blind, or utilize interpreters.

The CMS interpretive guidelines specifically include mental health advance directives (referred to as psychiatric advance directives). In accordance with state law, a mental health advance directive should be given the same respect and consideration that traditional advance directives for health care are given. As discussed, Washington law allows for the creation of mental health advance directives. The interpretive guidelines note that hospitals should carefully coordinate how the choices a patient expresses in a mental health advance directive balance against the rights and safety of staff, patients, and other individuals in the event a dangerous situation arises.

The interpretive guidelines stipulate that hospitals must take specific action if moral or ethical objections may hamper compliance with an advance directive. The policies the facility disseminates regarding advance directives must include a clear and precise statement of limitation if the hospital cannot implement an advance directive based on moral or ethical objections. These policies should clarify any differences between institution-wide and individual practitioner objections, reference state law that allows objections, and describe the range of procedures affected by the objections.(15)

Long-Term Care Facilities

The CMS established separate Conditions of Participation to address the use of advance directives in nursing facilities, skilled nursing facilities, and Critical Access Hospitals that provide long-term services.(16) This does not include facilities for the mentally retarded. The requirements that mirror the Patient Self-Determination Act apply equally to hospitals and long-term care facilities. The Conditions of Participation for long-term care facilities relevant to advance directives and end-of-life care state that:

- unless adjudged incompetent or found to be incapacitated under state law, residents have the right to participate in planning care and treatment or changes in care and treatment;

- residents (or representatives under state law) have the right to be fully informed of their total status, including medical condition, in a language that they can understand; and
- residents (or representatives under state law) have the right to refuse treatment, to refuse to participate in experimental research, and to formulate an advance directive.

The CMS issued interpretive guidelines to accompany these Conditions of Participation for long-term care facilities.(17) Facilities must promote these rights, and the exercise thereof, to each resident, including those who face barriers (such as communication problems, hearing problems, and cognition limits) in exercising those rights. Information should be presented in language that residents can understand ? this includes the use of translators for foreign and sign language, or other aides as necessary, while minimizing the use of technical jargon. If a resident has an advance directive, facilities are not required to provide care that conflicts with an advance directive. As with hospitals, long-term care facilities are not required to implement an advance directive if the provider has an objection, but must inform residents of these objections.

Joint Commission Accreditation

The Joint Commission (formerly the Joint Commission on Accreditation of Healthcare Organizations or JCAHO) addresses advance directives, end-of-life care, and surrogate decision-making standards in the *2006 Comprehensive Accreditation Manual for Hospitals*. All Joint Commission accredited facilities, including hospitals, outpatient clinics, and nursing homes, must adhere to Joint Commission standards in order to retain accreditation.

The Joint Commission addresses advance directives, end-of-life care, and surrogate decision-making in its Ethics, Rights, and Responsibilities Standards (RI). End-of-life care is also addressed in the Provision of Care, Treatment, and Services Standards (PC). The elements of performance that accompany the standards direct hospitals to provide patients with information about their right to accept or refuse medical treatment, including forgoing or withdrawing life-sustaining treatment or withholding resuscitative services. Specifically, information must be provided upon admission on the extent to which the hospital is able, unable, or unwilling to honor advance directives. Information should be conveyed in a way that is appropriate to the patient's age, understanding, and language.

The Joint Commission defines an advance directive to include living wills, durable powers of attorney, do-not-resuscitate orders, right to die, or similar documents listed in the Patient Self-Determination Act which express the patient's preferences. Though the Joint Commission's accreditation standards do not specifically address mental health advance directives, these directives fall under the obligations laid out in the Patient Self-Determination Act.

The following is a list of section numbers and titles from the *Comprehensive Accreditation Manual for Hospitals 2007* edition that address advance directives, end-of-life care, and surrogate decision-making.

Advance Directives

RI.2.10

The hospital respects the rights of patients.

Hospital policies and procedures must address the rights of each patient to:

- care, treatment, and services within the capability and mission of the hospital and in compliance with law and regulation;
- cultural, psychosocial, spiritual, and personal values, beliefs, and preferences respected;
- hospital support of the right to personal dignity; and
- accommodations for pastoral or other spiritual services.

RI.2.20

Patients receive information about their rights.

- Information is provided upon admission to each patient regarding patient rights and the extent to which the hospital is able, unable, or unwilling to honor advance directives.

RI.2.70

Patients have the right to refuse care, treatment, and services in accordance with law and regulation.

RI.2.100

The hospital respects the patient's right to and need for effective communication.

The hospital must provide:

- written information in a manner that is appropriate to the age, understanding, and language of the patient;
- interpretation services, including translation, as necessary; and
- services to address the needs of those with vision, speech, hearing, language, and cognitive impairments.

IM.6.10 and IM.6.20

The hospital has a complete and accurate medical record for patients assessed, cared for, treated, or served and the records contain patient specific information, as appropriate, to the care, treatment, and services provided.

End-of-Life Care

RI.2.30

Patients are involved in decisions about care, treatment, and services provided.

RI.2.80

The hospital addresses the rights and wishes of patients relating to end-of-life decisions.

Hospitals must comply with the following elements:

- have policies, in accordance with law and regulations, that address advance directives and the framework for forgoing or withdrawing life-sustaining treatment and withholding resuscitative services and consistently implement them;

- provide adult patients with written information about their rights to accept or refuse treatment and hospital policies addressing these rights;
- document the existence or absence of a patient's signed advance directive;
- document and honor, within the limits of the law or hospital capacity, a patients' wishes concerning organ donation;
- upon request, help or refer patients for assistance in formulating advance directives, including reviewing and revising existing directives; and
- have a mechanism for health care professionals and designated representatives to honor advance directives within in limits of the law or hospital capabilities.

In outpatient hospital settings, the hospital must:

- develop and implement policies addressing advance directives, specifying whether the hospital will honor the directives;
- inform patients and families of these policies upon request or as appropriate for care, treatment, and services provided; and
- help patients formulate advance directives or refer them to other entities for assistance.

RI.2.160

Patients have the right to pain management.

Hospitals must plan, support, and coordinate activities and resources to:

- assess for pain;
- educate all relevant providers about assessing and managing pain; and
- educate patients and families about their roles in managing pain, including the potential limitations and side effects of pain treatments.

PC.4.10

Development of a plan for care, treatment, and services is individualized and appropriate to the patient's needs, strengths, limitations, and goals.

PC.8.10

Pain is assessed in all patients.

PC.8.70

Comfort and dignity are optimized during end-of-life care.

- Hospital educate staff about the unique needs of dying patients and their families and caregivers.
-

Surrogate Decision-Making (18)

RI.2.30

Patients are involved in decisions about care, treatment, and services provided.

RI.2.70

Patients have the right to refuse care, treatment, and services in accordance with law and regulations.

Regulations on Nursing Homes in Washington

Washington state has regulations specifically applicable to nursing homes. Nursing homes must adhere to these requirements in addition to the federal and state law on advance directives discussed previously.

Washington Administrative Code 388-97-065, entitled “Advance Directives,” outlines requirements for nursing homes. These requirements are similar to those under the Patient Self-Determination Act, discussed at the beginning of this section. The term “advance directive” in this chapter of the WAC refers to any document indicating a resident’s choice with regard to a specific service, treatment, medication, or medical procedure option that may be implemented in the future. Examples of advance directives include a durable power of attorney for health care, a health care directive, a limited or restricted treatment order, and a DNR. Though mental health advance directives are not specifically referenced, nursing homes are directed to carry out the WAC in accordance with applicable state law. As mental health advance directives are state law, they are probably included in nursing homes’ obligations regarding advance directives.

Similar to the Patient Self-Determination Act requirements, under WAC 388-97-065, a nursing home must:

- inquire whether a resident has an advance directive and the nature of the directive;
- document in the clinical record whether or not the resident has an advance directive;
- not require that the resident have an advance directive;
- inform the resident in writing and orally, at the time of admission and as necessary thereafter, in language and words the resident understands, of the resident’s right to make health care decisions and the nursing homes policies and procedures concerning implementation of advance directives;
- inform the resident of the right to change his or her mind regarding previous decisions; and
- review the resident’s advance directive at the resident’s request, when the resident’s condition warrants review, and when there is a change in condition.

A resident’s advance directive might conflict with nursing home procedures and policies (which must be consistent with state and federal law). If this occurs, WAC 388-97-065 requires the nursing home to inform the resident of the procedures or policies that would preclude the home from implementing the resident’s advance directive. The resident must be provided with written policies and procedures that explain the circumstances under which the resident’s directive will or will not be implemented by the

nursing home. The nursing home should meet with the resident, discuss the conflict, and implement a plan to carry out the resident's wishes to the fullest extent possible. This plan should be attached to the advance directive and placed in the resident's chart. If the resident chooses to seek care elsewhere where his or her directive will be fully honored, the nursing home must assist the resident in locating other appropriate services.

In addition to advance directives, the regulations pertaining to nursing homes cover patient rights, informed consent, and guardianship. These regulations dictate that a nursing home must:

- protect and promote the right of residents, including the right to accept or refuse treatment;
- fully inform residents in advance, in language and words they understand, about care and treatment and of any changes in care or treatment that may affect residents' well-being; and
- document any refusal of care in the resident's comprehensive plan of care.

Nursing home regulations covering advance directives, patient rights, informed consent, and guardianship can be found in the following sections of the Washington Administrative Code:

- WAC 388-97-051 Residents Rights
- WAC 388-97-052 Free Choice
- WAC 388-97-055 Residential Decision-Making
- WAC 388-97-060 Informed Consent
- WAC 388-97-065 Advance Directives
- WAC 388-97-07005 Notice of Rights and Services
- WAC 388-97-090 Comprehensive Plan of Care

See Section Three for the full text of the federal and state regulations implementing the Patient Self-Determination Act, along with the relevant state statutes and regulations mentioned in this section.

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1. Patient Self-Determination Act, 42 U.S.C. § 1395cc (2000).
 2. 42 U.S.C § 1395cc(f)(3).
 3. A health care advance directive (aka a living will) expresses a competent individual's preferences regarding the withholding or withdrawal of life-sustaining treatment if terminally ill or permanently unconscious, *see* RCW 70.122. A durable power of attorney for health care appoints an agent to provide informed consent for health care decisions on behalf of the individual who executed the directive, *see* RCW 11.94.
 4. A mental health advance directive expresses a competent individual's preferences and instructions regarding his or her mental health treatment in the event of incapacitation. The

directive may also appoint an agent to make decisions on behalf of the person who executed the directive.

5. RCW 70.122.130.
6. RCW 70.122.130(2)(a).
7. RCW 70.122.130(2)(b).
8. RCW 70.122.130(c).
9. RCW 70.122.051(3).
10. RCW 70.122.051(4)(a-d).
11. Refer to 42 C.F.R § 489.102 for details regarding hospitals' obligations to educate patients and the community, have written policies, ensure compliance with state law, make timely inquiries regarding whether a patient has an advance directive.
12. 42 C.F.R § 482.13(b).
13. "For the purpose of this part, advance directive means a written instruction, such as a living will or durable power of attorney for health care, recognized under State law (whether statutory or as recognized by the courts of the State), relating to the provision of health care when the individual is incapacitated." 42 C.F.R § 489.100.
14. CMS *State Operations Manual*, Appendix A – Survey Protocol, Regulations and Interpretive Guidelines for Hospitals (Rev. 1, 05-21-04) A-0038 – A-0052.
15. Washington's Natural Death Act allows health care facilities or personnel to refuse to participate in the withholding or withdrawing of life-sustaining treatment due to moral or ethical objections. Patients must be informed of this policy or practice when the provider or facility becomes aware of the existence of a directive. RCW 70.122.060(2) & (4). Washington's Mental Health Advance Directive law also allows providers and facilities to decline to follow a patient's directive, but this must be clearly conveyed at the time the provider or facility receives the directive. RCW 71.32.150(5)(a). Refer to Section Two on Mental Health Advance Directives for further information.
16. 42 C.F.R § 483.10.
17. CMS *State Operations Manual*, Appendix PP – Guidance to Surveyors for Long-Term Care Facilities (Rev. 22, 12-15-06) and Appendix W – Survey Protocol, Regulations and Interpretive Guidelines for Critical Access Hospitals (CAHs) Swing-Beds in CAHs (Rev. 02-21-04).
18. See Section Five, Surrogate Decision-Making, for further information.

Section 2: Mental Health Advance Directives

In 2003, the Washington State Legislature enacted a law, codified as RCW 71.32, that provides for advance directives for mental health treatment. The law allows a person with capacity to state mental health treatment preferences in a legal document that will govern during periods of incapacity.(1) Mental health advance directives may be relevant to any time in an adult's life – during cyclical loss of capacity or as part of the aging and end-of-life process.(2) (See Section Three for the full text of RCW 71.32.)

In addition to an overview of the Mental Health Advance Directive Law, this section includes:

- [MHAD Bulletin](#)
- [PowerPoint presentation](#)
- [a list of additional resources](#)
- [model hospital policies on mental health advance directives](#) (MS Word)
- [a clinicians' checklist for mental health advance directives](#) (PDF)
- a patient brochure on mental health advance directives ([English](#)) / ([Spanish](#)) (PDF)
- [a sample mental health advance directive](#) (PDF)

A validly executed mental health advance directive is generally binding and must be respected by agents, guardians, surrogate decision-makers, health care providers, professional persons, and health care facilities.(3) Health care facilities include hospitals, institutions, state hospitals, nursing homes, and clinics that are part of a community mental health service delivery system.(4) Only these facilities are required to comply with directives, but clinicians who fit the statutory categories are required to comply no matter what the setting. The statute covers: health care providers (osteopathic physicians or osteopathic physician's assistants, physician or physician's assistant, and advance registered nurse practitioners), mental health professionals (psychiatrists, psychologists, psychiatric nurses, and social workers), and professional persons (mental health professionals and any personnel added by the secretary of DSHS).(5)

To be valid, a mental health advance directive must:

- be in writing;
- include language indicating a clear intent to create a directive;
- be dated and signed by the patient, or be dated and signed in the patient's presence at his or her direction;
- state whether the directive may or may not be revoked during a period of incapacity;
- be witnessed in writing by at least two adult witnesses;(6) and
- conform substantially to the statutory format.(7)

The principal – the person completing the mental health advance directive – may utilize a directive to: consent to specific treatment, refuse specific treatment, consent to short-term inpatient treatment (up to 14 days), appoint an agent, suggest alternative treatments, and offer insight to health care providers about common triggers and reactions to treatment.

Appointment of an agent does not change the restrictions placed on guardians to consent to treatments(8) – but the law allows agents to consent if they are following a directive. The directive must include an expiration date, but if a principal is incapacitated when the directive is meant to expire, the directive remains effective until the principal regains capacity.(9) A sample advance directive is included in this section for reference.

The principal must indicate in the directive whether he or she may revoke during periods of incapacity or wishes to be unable to revoke while incapacitated.(10) By choosing to make a directive irrevocable while incapacitated, a principal effectively waives the right to refuse treatment consented to in the directive. If the principal allows for revocation while incapacitated, he or she may change the directive at any point, including any and all consent to admission to a treatment facility.

The principal may include in a mental health advance directive any provision relating to mental health treatment, the care of the principal, or the care of the principal's personal affairs. Health care facilities and providers are under no obligation to follow the portions of a directive that deal with personal affairs.

As discussed in Section One, the federal Patient Self-Determination Act (PSDA) requires health care facilities to educate patients and the community about advance directives, maintain policies and procedures on advance directives, and inquire on admission whether the patient has made an advance directive. Mental health advance directives are included under the PSDA's requirements. (Refer to Section One for further discussion of hospital obligations under the PSDA.) In addition to the PSDA requirements, providers licensed or certified by DSHS must also advise clients of their rights to make physical and mental health advance directives.(11)

The existence of a directive may not be used as a criterion for insurance, a condition for receiving mental or physical health care services, or as a condition of admission to or discharge from a health care facility or long-term care facility. Health care facilities must inform and educate patients about directives, but may not make their presence or absence mandatory.

Washington's Mental Health Advance Directive Law imposes timelines and duties on facilities and providers in order to safeguard patients' rights. Many of these obligations center on determinations of capacity. For the purposes of mental health advance directives, "capacity" is essentially the ability to give informed consent.(12) Informed consent is defined in the Mental Health Advance Directive law as consent that is given after a person:

- a. is provided with a description of the nature, character, and anticipated results of proposed treatment and alternatives and the recognized serious possible risks, complications, and anticipated benefits in the treatment and alternatives, including nontreatment, in language that the person can reasonably be expected to understand; or
- b. elects not to be given the information included in (a).(13)

A principal is incapacitated if he or she is “unable to understand the nature, character, and anticipated results of proposed treatment or alternatives; understand the recognized serious possible risks, complications, and anticipated benefits in treatment; or communicate his or her understanding or treatment decisions.”(14)

The statutory mental health advance directive form clearly states that the principal, in signing the form, intends the directive to give informed consent to the treatment and admission specified. Mental health advance directives are a legal method of informed consent. Even if the principal is found to be incapacitated, providers may use a directive as informed consent for the items documented in the directive. However, the mere existence of a mental health advance directive does not mean the person is presently incapable of providing informed consent.

Most directives do not become operational until the principal is found incapacitated. As capacity is presumed under the statute, capacity must be disproved.(15) Capacity determinations must be made as prescribed by law. Capacity must be initially assessed and regularly reevaluated according to the timeframes in the statute, which allow no flexibility or deviation. A principal, agent, provider, or professional person may seek a determination as to whether the principal is incapacitated or has regained capacity. If a determination of capacity is not made within the timeframes outlined below, the principal is judged to have capacity and must be treated accordingly.(16)

To ensure compliance with the Mental Health Advance Directive law, health care facilities must:

- make an initial determination of capacity within 48 hours of an initial request;
- not treat the principal until the initial determination is made – unless the principal consents or treatment is authorized by state or federal law. If the patient is already being treated according to a directive, the treatment may continue while a determination is pending;
- ensure that a capacity determination is conducted by two health care providers, or by one mental health provider and one health care provider.(17) At least one person making the determination must be a psychiatrist, psychologist, or psychiatric nurse practitioner.(18) The principal must be personally examined by at least one mental health professional or health care provider prior to the capacity determination;
- promptly advise the principal that a capacity determination is sought, if someone other than the principal or his or her agent request it;
- advise the principal that he or she may demand that the capacity determination be made by a court. If the principal requests a court determination, the facility must make reasonable efforts to notify the person legally authorized to make decisions for the principal. If the principal or interested party requests a court determination, at least one mental health professional familiar with the principal must testify and the principal must have an opportunity to appear in court (unless there is good cause that the principal not be in court);
- in an inpatient setting, reevaluate capacity within 72 hours of admission or when a change in the principal’s condition indicates a regaining of capacity – whichever occurs first;
- after 72 hours of inpatient treatment, reevaluate the principal when his or her condition indicates capacity may be regained;

- in an outpatient setting, reevaluate capacity within 5 days of a request for a determination; and
- reevaluate capacity within 72 hours if the principal requests a redetermination.(19)

There is specific statutory instruction for a person who is presently refusing admission, but consented at an earlier time via an advance directive and made the directive irrevocable.(20) For a facility to admit the principal based on the directive the following must occur:

- a physician must evaluate the principal's mental condition and, along with another provider or mental health professional, determine that the principal is incapacitated;
- the principal's agent (if one exists) must give informed consent;
- the physician must document the principal's need for inpatient evaluation or treatment that is not available in a less restrictive setting; and
- the physician documents a summary of findings and recommendations in the medical record. If the physician is not a psychiatrist, the principal must be assessed by a mental health professional within 24 hours of admission.

At the end of the period of voluntary commitment consented to in a directive, but no longer than 14 days after admission, a patient who has not regained capacity or has regained capacity, but refuses to remain, must be discharged. The principal may not be kept longer than 14 days and must be released during reasonable, daylight hours. The exception to this timeframe is involuntary detention, which may supersede the period of consent in a directive.(21) Under the mental health advance directive statute, a principal who takes action demonstrating a desire to be discharged and makes statements to that effect, must be discharged. If a patient presents a likelihood of serious harm or is gravely disabled, the patient may be held for evaluation under the state involuntary treatment law.

The principal may request a redetermination of capacity, request that any determination be made by a court, and/or bring action in court to contest the validity of his or her directive. Directives also do not create an obligation for a provider to pay the costs associated with the treatment requested.(22) There is no mention in the statute regarding the use of public funds for capacity determinations or redeterminations. Facilities and providers are not obligated to assume these costs – directives do not create an entitlement to care. Coverage by private or governmental payers turns on whether determinations are medically necessary. Determinations on admission or upon a change in condition may be covered, but determinations requested by a principal or agent may not be deemed medically necessary.

RCW 71.32 explicitly states that mental health advance directives do not create an entitlement to mental health or medical treatment, do not supersede a determination of medical necessity, and do not obligate provision of treatment that is unavailable.(23) Additionally, a directive does not create a doctor-patient relationship if one does not previously exist. Placement and treatment must be based on the clinical needs of the patient and the interests of the facility at large. Thus, while a principal's request for a specific physician should be honored if possible, it may be denied if the physician's patient load, specialty, ward assignment, or other factors make them unavailable. Similarly, providers should follow standard procedures whenever the principal requests care that is not covered by insurance or when the

principal is uninsured. Facilities must initiate policies and procedures that detail how to evaluate and act upon directives in ways that are manageable by the facility.

Portions of the directive regarding nontreatment personal care of the principal or principal's personal affairs do not compel action by a provider. Portions of the form detailing childcare, notification, or financial affairs are not the responsibility of providers or facilities.

When a provider is presented with a mental health advance directive, he or she is deemed to have actual knowledge of its contents and is obligated to act upon the directive and make it a part of the patient's record. However, there are instances in which facilities and providers may refuse to follow a patient's mental health advance directive. The exceptions to this duty include:

- if the provider is unable or unwilling to comply with any portion of a directive, the provider may object upon initial receipt of the directive. Providers may object to any part or parts of the directive for any reason, but must promptly notify the principal and his or her agent and document the reasons for refusal in the principal's medical record. Portions of the directive that are not objectionable must be followed;(24)
- if the principal is subject to a court order, his or her mental health advance directive may be superseded or revoked; or
- in the event of involuntary commitment, portions of a mental health advance directive that are inconsistent with the purpose of commitment are not binding, but are considered advisory.

While acting under authority of a directive, a provider or facility must act in accordance with the directive to the fullest extent possible with four exceptions. Facilities and/or providers may decline to follow a part or parts of a mental health advance directive if:

- compliance with a portion of the directive would violate the accepted standard of care;
- the requested treatment is not available;
- compliance would violate the law; or
- the situation constitutes an emergency and compliance would endanger any person's life or health.(25)

If any of these exceptions occur, the principal and agent must be notified and the reasoning must be noted in the medical record. As with an initial objection, all remaining portions of the directive must be followed.

Providers are not subject to civil liability or sanctions when a directive is not followed or treatment is not provided due to any of the above reasons. Immunity is also conveyed for treatment, in good faith and without negligence, in compliance with a directive, in absence of actual knowledge of the existence of a directive, and in compliance with a directive that the provider does not know has been revoked. Additionally, a determination of capacity, treatment based on such a determination, and treatment based on a presumably legal but actually invalid directive also convey immunity.

As noted in previous sections, Washington law provides both civil and criminal immunity, as well as immunity from professional sanctions, for providers who act in good faith, and without negligence, in

compliance with an advance directive under the Natural Death Act. The Mental Health Advance Directive Law provides immunity only from civil liability and professional sanctions.(26) This disparity and the lack of criminal immunity for mental health advance directives are not explained in the statute.

Special concerns for long-term care facilities

Long-term care facilities are specifically addressed in RCW 71.32.250. These facilities include nursing homes, nursing facilities, any swing bed in an acute care facility, family or group homes, and facilities specializing in alcoholism, mental retardation, or mental, emotional, or behavioral problems.(27) These facilities must readmit residents who leave the facility for inpatient mental health treatment based on a mental health advance directive if the resident's physical condition is the same as it was during the original admission to the facility.

The facility must readmit the resident:

- so long as the staff determines that he or she is no longer in need of inpatient mental health treatment; or
- the consent to inpatient treatment in the directive has expired.

If the long-term care facility no longer has bed space for the principal at the time he or she is discharged, the treating facility may consult with the resident and agent and discharge the resident to another facility. The discharge must be accompanied by appropriate discharge plans. The statute does not restrict the resident's right to early release from inpatient mental health treatment and does not restrict legal transfers or discharges.

When the statute was passed in 2003, the Joint Legislative Audit and Review Committee was instructed to evaluate the operation and impact of this portion of the statute and report back by December 2004. The committee completed its report but found very little to discuss. Though state-funded facilities were informing patients of their rights to have mental health advance directives, few, if any, nursing home residents completed directives. The committee noted that there remained the possibility that directives might be used to remove problematic patients and recommended that a follow up study be conducted in two to three years. No additional study appears to have been conducted.

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1. Under the Mental Health Advance Directive Law, an adult is presumed to have capacity so long as he or she has not been found incapacitated under the mental health advance directive procedures or under the Washington state guardianship statute. RCW 71.32.020(3) and RCW 71.32.040.
 2. Mental health advance directives do *not* replace or alter the Involuntary Treatment Act – involuntary civil commitment is a separate process with different standards and decision-making protocol. Mental health advance directives cannot be used to consent to civil commitment.
 3. RCW 71.32.010.

4. RCW 71.32.020(5).
5. RCW 71.32.020(6), (12), & (14).
6. See RCW 71.32.090 for detailed information on who may not serve as a witness.
7. RCW 71.32.060(1).
8. RCW 11.92.043(5) restricts the authority of guardians to consent to convulsion inducing therapy, surgery solely for purpose of psychosurgery, or mental health treatment that restricts physical freedom of movement.
9. RCW 71.32.080(6).
10. RCW 71.32.060(1)(d).
11. WAC 388-865-0410.
12. Informed consent under the Mental Health Advance Directive law closely follows the definitions provided in RCW 7.70.050.
13. RCW 71.32.020(8).
14. RCW 71.32.020(7).
15. RCW 71.32.040.
16. RCW 71.32.130(4).
17. RCW 71.32.110(2)(a).
18. RCW 71.32.110(2)(b).
19. These requirements are listed in RCW 71.32.110 and RCW 71.32.130.
20. RCW 71.32.140.
21. RCW 71.32.140(6)(b), see also RCW 71.05.050 regarding detention and evaluation for civil commitment.
22. RCW 71.32.070(2). Also, unless otherwise agreed, agents have no obligation to pay for the principal's treatment.
23. RCW 71.32.070.
24. Recall that under the PSDA, facilities must provide patients with notice if there are any institution-wide or provider specific objections to following an advance directive. See Section One for more information.
25. RCW 71.32.150(2).
26. RCW 71.32.170.
27. RCW 71.32.020(9). Long-term care facilities are defined in RCW 43.190.020.

Section 3: Statutes and Regulations on Advance Directives

The following pages are the actual text of state and federal statutes and regulations relevant to end-of-life advance directives, as discussed in Chapters 1 and 4. They are current as of November 2001.

Washington State's Natural Death Act Statute

[Chapter 70.122 RCW](#)

Mental Health Advance Directives Statute

[Chapter 71.32 RCW](#)

Washington State's Power of Attorney Statute

[Chapter 11.94 RCW](#)

Washington Regulations for Serving Medical Assistance Clients

[WACs 388-501-0125](#)

Washington State Regulations for Nursing Homes

[WACs 388-97-051 through 388-97-07005](#)

Medicare and Medicaid Conditions of Participation on Advance Directives and Patients' Rights

[42 CFR 489.102; 42 CFR 482.13](#)

Federal Regulations Implementing the Patient Self-Determination Act

[42 CFR Part- 417 et al.](#)

Section 4: Establishing Policies and Procedures on Advance Directives

As introduced in Section One of this manual, the Patient Self-Determination Act (PSDA) requires hospitals and other facilities to establish written policies and procedures on advance directives and act upon them. Failure to comply could result in non-renewal or termination of a Medicare Provider Agreement.

These policies and procedures must be developed by the hospital to suit the needs of the institution. Involve an attorney in the development and/or review of the entire plan. Here are suggestions to start the process:

1. Promulgate a general POLICY on advance directives setting forth the hospital's intention to comply with the PSDA and to assist patients, staff, and the community in understanding advance directives – specifically, what they are and their purpose. Promulgate a general POLICY on advance directives setting forth the hospital's intention to comply with the PSDA and to assist patients, staff, and the community in understanding advance directives – specifically, what they are and their purpose. The policy must explicitly state that the hospital will not discriminate against patients based on whether or not they have advance directives.
2. The policy must explicitly state that the hospital will not discriminate against patients based on whether or not they have advance directives.
 - a. designate when, where, and who in the hospital will ask patients whether they have advance directives and when the Washington State Living Will Registry will be consulted (see <http://www.doh.wa.gov/livingwill/>);
 - b. provide for documentation of patient responses in their medical records;
 - c. indicate whether or not the hospital will require copies of the health care directive, durable power of attorney for health care, or mental health advance directive documents, and if so, how the hospital will ask for them and where they will be kept when received; and
 - d. explain the hospital's policies for honoring advance directives. If they conflict with the patient's wishes, the hospital should make a statement which at a minimum:
 - i. clarifies any differences between institution-made moral or ethical objections and those that may be raised by individual providers;
 - ii. identifies the state legal authority permitting such objections; and
 - iii. describes the range of medical conditions or procedures affected by any moral or ethical objections. If the patient chooses to stay under the hospital or physician's care, the hospital must agree upon a written plan of action and enter it into the medical record;
 - e. assure that each patient is given clear, concise, written information about applicable state law (both by statute and by the courts) and the hospital policy on advance directives;
 - f. explain how the hospital will carry out the community and staff education requirements;
 - g. provide for accurate record keeping of the action the hospital takes to meet the requirements of the law;
 - h. provide for periodic evaluation of the effectiveness of these policies, procedures, and programs in meeting the PSDA's requirements; and

- i. indicate whether or not the hospital will provide patients with health care directive, durable power of attorney for health care, and mental health advance directive forms. This decision should be made in consultation with an attorney. This manual includes sample forms for all three types of directives. They are to assist each hospital, in consultation with its attorney, in developing its own suggested forms for its patients' use, if it will be the hospital's policy to provide patients with forms in addition to the obligation to inform its patients of their rights to formulate advance directives. Another good source for an advance directive document is the "5 Wishes" program (see: <http://www.agingwithdignity.org/5wishes.html>)
3. As facilities develop policies and procedures to meet the PSDA requirements, existing instructions may need to be reviewed and/or revised. Relevant instructions include:
 - a. how the hospital identifies patients with a terminal condition;
 - b. how the hospital manages terminal patients while they are in the hospital;
 - c. how the hospital manages patients in a coma or persistent vegetative state (PVS);
 - d. the hospital's position on use of artificial nutrition and hydration for terminal, PVS, and coma patients;
 - e. how the hospital communicates with and involves the families or other patient representatives in medical care decisions;
 - f. how patients (or their representatives) are told that, under Washington law, they have the right to control decisions about their own medical care, including whether life-sustaining procedures are to be withheld or withdrawn in case of terminal illness;
 - g. whether or not a health care directive, durable power of attorney for health care, or mental health care advance directive makes a difference in the handling of the patient and, if so, under what conditions; and
 - h. how the hospital's policies and procedures on advance directives relate to the hospital's policies and procedures on the POLST form (see Section Six of this manual).

Suggestions On How To Meet Community Education Requirements

The Patient Self-Determination Act requires hospitals to educate the community about advance directives. The educational materials must inform members of the public of their rights under state law to make decisions about their medical care, the right to formulate an advance directive, and the hospital's implementation policies concerning an individual's advance directive.

The community efforts may be carried out in a variety of methods or formats – such as health fairs, seminars, or workshops. The statute allows facilities to join with others to fulfill the education requirements. A provider must be able to document its community education efforts. Documentation may include simply maintaining copies of any materials used, such as a brochure. A [sample brochure on advance directives](#) is included in this section. (See Section Two for a sample brochure on mental health advance directives.)

The same materials used to inform patients of their rights regarding advance directives may also be used to meet the community education requirement.

Here are some possible ways to accomplish the community education required by law:

1. Distribute written materials at every opportunity, not just when patients are admitted. Here are some ways this might be done:
 - a. Medical staff can provide information to patients in their offices.
 - b. Senior citizens centers or senior citizen groups may distribute the information in a variety of ways.
 - c. The local library might put materials in its collection.
 - d. If community groups ask for information about the hospital, include materials on advance directives.
 - e. Employers and labor unions may be interested in providing the information to their staff and members.
 - f. Give this material to adults who tour or visit the hospital.
 - g. Use public service announcements on radio and/or television, and newspaper stories or advertisements to offer the brochures to the public.
 - h. Keep track of how materials are distributed, periodically reviewing the program to decide if there are other opportunities to reach people.
2. Sponsor periodic community forums. Though forums are time consuming because they require careful planning, they are often worth the effort. A hospital may hold them as frequently or infrequently as needed in the community. They can be as simple as one knowledgeable person explaining the law or more complicated, such as convening a panel to present information and answer questions.
3. Seek opportunities to meet with community groups. Some groups may want to join with the hospital to develop and present community education programs. Good liaisons can enhance the quality of the program and increase the number of people reached. Another idea is to seek out community organizations and ask if they are receptive to a presentation during a meeting. Keep records of contacts. Review the list periodically to decide which groups have been missed and what opportunities are available for reaching new groups.
4. Work with news media. News media can be helpful in any community education program. Here are some ways to incorporate them:
 - a. Use news releases to tell the media about the law and education programs undertaken.
 - b. Offer an expert spokesperson to the media for interviews. This could result in a routine news story, feature story, television or radio interview, or an appearance on a talk show. The media will find real stories about the ethical dilemmas and struggles of medical providers compelling, but remember the duty to guard the privacy of individual patients.
 - c. Offer patient information materials or announce events through radio and television public service announcements.
 - d. Talk to the local media owners, editors, and/or managers about the project and ask for editorial support. Submit opinion pieces stating views on the need for advance directives.

Any combination of these suggestions may be utilized to undertake community education. The most important part of doing this correctly is knowing the community and assessing how best to reach it. Think about the community and the people who might be interested in advance directives. Elderly and retired people come immediately to mind – but what about younger people just starting families? They may be ready to make orderly life plans. An obstetrics unit may provide a link to these younger individuals.

A second important step is to develop at least one expert on the subject of advance directives. Chances are that there is someone in the community with an interest in this issue. If no one on the hospital staff is available, there might be an attorney, clergy member, or physician with particular expertise. Finding a person or persons truly interested in this topic, who have the sensitivity and enthusiasm to talk about it, can make or break a project.

Sample Advance Directive Forms

- Health Care Directive (or Living Will) [\(English\)](#) / [\(Spanish\)](#) (PDF)
- Durable Power of Attorney for Health Care [\(English\)](#) / [\(Spanish\)](#) (PDF)

Section 5: Surrogate Decision-Making

State and federal law recognizes an incompetent individual's right to autonomy and self-determination. In Washington State, there are two mechanisms for effectuating an incompetent individual's right to make health care decisions: advance directives and surrogate decision-making. In the absence of an advance directive, state law allows surrogates to make medical decisions for incompetent individuals. This section will focus on surrogate decision-making in the context of guardianships and informed consent. The Washington State statutes on guardianship and informed consent are included at the end of this section (see Section Three for the text of the Washington Administrative Code mentioned in this section.)

The sections below have been excerpted from the Washington Health Law Manual with permission of the publishers (the Washington State Society of Healthcare Attorneys and the Washington State Hospital Association) and by the chapter's author, Professor Annette Clark, J.D., M.D. The Joint Commission standards and recent updates to the statutory information have been added.

Statutory Authorization for Surrogate Decision-Making

Most individuals have not executed advance directives under the Natural Death Act. In the absence of an advance directive, medical decisions for an incompetent person are made by a surrogate decision-maker. In Washington, the persons authorized to make medical decisions on behalf of an incompetent individual are as follows, in order of priority:

1. the appointed guardian of the patient, if any;
2. the individual, if any, to whom the patient has given a durable power of attorney that encompasses the authority to make health care decisions;
3. the patient's spouse or state registered domestic partner;(1)
4. children of the patient who are at least eighteen years of age;
5. parents of the patient; and
6. adult brothers and sisters of the patient.(2)

As indicated by the second statutory class listed above, an individual may execute, while competent, a durable power of attorney for health care. The effect of this instrument is to authorize the attorney-in-fact to provide informed consent for health care decisions on the principal's (incompetent individual's) behalf.(3) The attorney-in-fact is second only to a court-appointed guardian in decision-making priority under Washington's informed consent statute.(4)

The surrogate decision-making statute specifies that a physician who is seeking informed consent for an incompetent patient, and who has been unsuccessful in locating and obtaining authorization from a competent person in the first or succeeding class, may seek consent from any person in the next class in the order of descending priority.(5) However, a person who has lower priority may not consent if a person of higher priority has refused, and a person in the same class with two or more individuals may not give informed consent unless the decision is unanimous.(6)

While the statute dictates a rather rigid hierarchy for surrogate decision-making, in practice, health care providers naturally turn to family members and loved ones to make medical decisions for incompetent patients. The statutory designation of decision-making priority plausibly has the most effect in situations

where the family members, loved ones, and health care providers cannot reach agreement on the appropriate treatment choice.

Standards and Procedures for Surrogate Decision-Making

Substituted Judgment Standard

A surrogate decision-maker must use the doctrine of substituted judgment in consenting to or refusing health care on behalf of an incompetent individual. The standard applies to all medical decisions, whether they involve the discontinuation of life-sustaining treatment or a choice between alternate medical treatments. (7) In each case, the substituted judgment standard requires that the surrogate decision-maker (whether a guardian, attorney-in-fact with authority to make health care decisions, family member, or the court) determine whether the patient, if competent, would have consented to the proposed health care. (8) The surrogate should consider all relevant factors that would influence the patient's medical treatment decisions, including:

- the person's prior statements regarding medical treatment;(9)
- the person's express wishes, even if made while the individual is incompetent;
- the patient's religious or moral views regarding medical care or the dying process;
- the person's prognosis if no treatment is given;
- the prognosis if one treatment is chosen over another;
- the risk of adverse side effects from the proposed treatment;
- the intrusiveness or severity of the proposed treatment;
- the ability of the patient to cooperate and assist with post-treatment therapy; and
- the wishes of family and friends, if those wishes would have influenced the patient.(10)

The Washington Supreme Court has specifically stated that judicial intervention is not generally required when a surrogate decision-maker exercises substituted judgment to make a treatment decision for an incompetent individual. (11) If the substituted judgment is made in a clinical setting, it will likely be acted upon unless family members or health care providers strongly disagree with the decision.

Best-Interests Standard

When a surrogate decision-maker cannot in good faith ascertain whether the patient, if competent, would have consented to the proposed health care, he or she must determine that the medical treatment is in the patient's best interests before giving consent.(12) Where the patient has never been competent, the substituted judgment standard is arguably meaningless, and so the best-interests standard is used instead.(13) Factors that should be considered by the surrogate decision-maker in determining whether medical treatment is in the best interests of the incompetent individual include:

- the patient's present level of physical, sensory, emotional, and cognitive functioning;
- the various treatment options and the risks, side effects, and benefits of each of the options;
- the life expectancy and prognosis for recovery with and without treatment;
- the degree of physical pain resulting from the medical condition, treatment, or termination of treatment; and
- the degree of dependency and loss of dignity resulting from the medical condition and treatment.(14)

Judicial Intervention in the Decision-Making Process

Any participant in health care decision-making for an incompetent individual, whether a guardian, attorney-in-fact with authority to make health care decisions, a physician or hospital, or family member, may petition the court for intervention in the medical decision-making process. (15) This occurs most often when family members or health care providers cannot agree on a course of action, particularly with regard to life-sustaining treatment, or where the court is statutorily required to authorize treatment for an incompetent individual. As part of the judicial process, the court will appoint a guardian ad litem to ascertain whether a patient, if competent, would have consented to or refused the medical treatment in question. (16)

Role of the Guardian in Medical Decision-Making for Incompetent Individuals

A court-appointed guardian has the legal right and responsibility to make medical decisions for the incompetent individual, and has priority over the other surrogate decision-makers under Washington's informed consent statute. (17) In the case of a limited guardianship, the limited guardian may make medical decisions for the incompetent individual where the power to make medical decisions is specifically authorized in the court's order, or where the power is not specifically excluded. (18)

General Powers

Consistent with RCW 7.70.065, a guardian is legally empowered to provide informed consent for health care for the incapacitated individual.(19) In doing so, the guardian is charged with asserting the incapacitated individual's rights and best interests.(20) As a surrogate decision-maker, the guardian is to make health care decisions through the use of the substituted judgment or best interests standards as described above. In addition, an individual's advance directive may specify that a guardian or other surrogate decision-maker is to be guided by the directive and any other clear expressions of his or her desires.(21) Even in the absence of such language, an advance directive may be useful in determining what treatment choices the individual would have made if competent.

Standby Guardian

The person appointed by the court as guardian or limited guardian must file a notice with the court designating a standby guardian or limited guardian. (22) In the event that informed consent for a necessary medical procedure is needed and the guardian or limited guardian cannot be located within four hours of the need for consent arising, the standby guardian or limited guardian may give informed consent. (23)

Limitation on Powers

The guardianship statute prohibits guardians from authorizing certain therapies or procedures. For example, if a guardian believes the incapacitated individual requires involuntary civil commitment for mental health treatment, the statutory procedures for involuntary commitment must be followed.(24) In addition, if the guardian believes any of the following procedures are necessary for the proper care of the incompetent person, the guardian must petition the court for an order authorizing the treatment or therapy:

- therapy or other procedures which induce convulsions;
- surgery solely for the purpose of psychosurgery; and

- other psychiatric or mental health procedures that restrict physical freedom of movement, or the rights set forth in RCW 71.05.370.(25)

In construing this statute, the Supreme Court of Washington stated that the intent of the statutory limitations is to require court approval before the guardian may consent to highly invasive, irreversible medical treatment that would seriously affect the incompetent person's bodily integrity. (26) This leaves open the possibility that judicial authorization may be required before a guardian may consent to other invasive, irreversible procedures even though the procedures are not on the statutory list. (27) In addition, before an incompetent person may be sterilized, a guardian ad litem must be appointed to represent the incompetent person's wishes and a court order must be obtained. (28)

Special Considerations

Nursing Home Residents

Resident rights regulations entitle residents of nursing homes in the State of Washington to specific rights relating to decision-making, including rights related to health care decision-making.(29) In general, the resident rights regulations ensure that nursing homes respect the decision-making authority of their residents, or in the case of incapacity, that a nursing home is aware of the identity of the surrogate decision-maker and the scope of authority granted to that person. The regulations provide that upon admission, the nursing home must determine:

- whether the resident has appointed another person to make health care decisions;
- whether the resident has created any advance directive (which includes power of attorney, health care directive, code/no code order, anatomical gifts, etc.) or other legal document that establishes a surrogate decision-maker in the future; and
- if the resident is not making decisions, who has the authority for surrogate decision-making and the scope of the authority.(30)

In fulfilling its duty, the nursing home must seek copies of any legal documents that establish the surrogate decision-maker's authority and document in the resident's clinical record the surrogate's name, address, and scope of authority, and the location of the legal documents within the facility. (31) A nursing home may not require a resident to have an advance directive or condition care on the basis of whether or not the resident has executed an advance directive. (32)

The resident rights regulations entitle the resident to a presumption of decision-making authority, which can be overcome if a court has established a guardianship, the resident has made a voluntary appointment of a surrogate decision-maker, a surrogate has been established by a legal document, or the facility has determined that the resident is an incapacitated individual, as defined by RCW 11.88.010 and WAC 388-97-065(3)(a) (regarding the demonstrated inability to make decisions over time, creating a significant risk of personal harm). (33) If the resident has been adjudicated by a court to be incompetent, the court-appointed guardian is the surrogate decision-maker. (34) If the resident has been determined to be incapacitated, but has not been adjudicated as incompetent, the surrogate decision-maker is established through either a legal document, such as a durable power of attorney for health care, or by state law, including the priority list of surrogate decision-makers contained within RCW 7.70.065. (35) When a nursing home has consulted a surrogate decision-maker to exercise the resident's rights, the nursing home must inform the resident of that fact and provide the resident with the information and opportunity to participate in decision-making to the greatest extent possible. (36)

Finally, if at some point the resident regains decision-making capacity, the nursing home must cease to rely on the surrogate decision-maker unless a court order or the resident directs otherwise. (37)

Children

The age of majority in Washington is eighteen. (38) Individuals under the age of eighteen generally lack the legal competency to make their own health care decisions, so a parent, legal guardian, or other authorized adult (39) must give consent. If the minor's parents are married, either parent may give consent to medical treatment, (40) but consent from both parents should be obtained if circumstances permit. In the case of consent for medical care for children, a number of exceptions and special statutory provisions apply, depending upon the custody and status of the minor and the type of care at issue (e.g., sexually transmitted diseases, abortion, mental health treatment, alcoholism, drug addiction, and treatment for sexually transmitted diseases).

Medical Emergencies

Actual informed consent for medical treatment is not required in the event of an emergency; consent is implied under the law. Pursuant to RCW 7.70.050, "If a recognized health care emergency exists and the patient is not legally competent to give an informed consent and/or a person legally authorized to consent on behalf of the patient is not readily available, his consent to required treatment will be implied." (41) This statutory provision is applicable both in circumstances where the individual was legally incompetent to make decisions prior to the medical emergency (e.g., a minor or someone adjudicated incompetent) and where the individual has been rendered incapacitated by the health care emergency.

The Joint Commission Accreditation

The Joint Commission has issued standards addressing surrogate decision-making and guardianship services. Any Joint Commission-accredited facility, including hospitals, outpatient clinics, and nursing homes must adhere to Joint Commission standards in order to retain its accreditation.

The following Joint Commission standards address these issues: (42)

RI.2.30

Patients are involved in decisions about care, treatment, and services provided.

- A surrogate decision-maker, as allowed by law, is identified when a patient cannot make decisions about his or her care, treatment, or service.
- The legally responsible representative approves care, treatment, and service decisions.
- The family, as appropriate and as allowed by law, with permission of the patient or surrogate decision-maker, is involved in care, treatment, and services decisions.

RI.2.70

Patients have the right to refuse care, treatment, and services in accordance with law and regulations.

- When the patient is not legally responsible, the surrogate decision-maker, as allowed by law, has the right to refuse care, treatment, and services on the patient's behalf.

RI.2.170

Patients have a right to access protective and advocacy services.

- When the hospital serves a population of patients who often need protective services, the facility develops and implements policies and procedures to provide resources to help the family and the courts determine the patient's needs for such services.
- When appropriate, the hospital maintains a list of names, addresses, and telephone numbers of pertinent state client advocacy groups and provides this list to patients upon request.

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1. RCW 7.70.065(1)(iii) was altered in 2007 by the Domestic Partnership Law (see Substitute Senate Bill 5336). The addition of state registered domestic partners to those who may provide informed consent came into effect on July 22, 2007.
 2. RCW 7.70.065(1).
 3. RCW 11.94.010(3).
 4. See RCW 7.70.065(1)(a).
 5. RCW 7.70.065(1)(b).
 6. RCW 7.70.065(1)(b)(i-ii).
 7. *In re Ingram*, 102 Wn.2d 827, 839, 689 P.2d 1363 (1984).
 8. RCW 7.70.065(1)(c). See also, *In re Colyer*, 99 Wn.2d 114, 137, 660 P.2d 738 (1983) (holding that life-sustaining treatment may be withdrawn if it is the guardian's judgment that the patient, if competent, would have chosen to withdraw treatment).
 9. The weight to be given to prior statements depends upon the age and maturity of the person, the context of the statements and the connection between the statements and the patient's condition. *In re Grant*, 109 Wn.2d 545, 567, 747 P.2d 445 (1987).
 10. *In re Ingram*, 102 Wn.2d at 840.
 11. *In re Colyer*, 99 Wn.2d at 127-128.
 12. RCW 7.70.065(1)(c). See also, *In re Grant*, 109 Wn.2d at 567-68.
 13. See *In re Hamlin*, 102 Wn.2d 810, 814-15, 689 P.2d 1372 (1984).
 14. *In re Grant*, 109 Wn.2d at 568.
 15. *In re Colyer*, 99 Wn.2d at 136.
 16. *In re Hamlin*, 102 Wn.2d at 816-817.

17. RCW 7.70.065(1).
18. RCW 11.88.095(3).
19. RCW 11.92.043(5).
20. RCW 11.92.043(4).
21. RCW 70.122.030(1)(b).
22. RCW 11.88.125(1).
23. RCW 11.92.043(5); *see also* RCW 11.88.125(3) (granting authority to the standby guardian to give informed consent as authorized in RCW 11.92.40).
24. RCW 11.92.043(5).
25. RCW 11.92.043(5)(a-c).
26. *In re Ingram*, 102 Wn.2d at 837.
27. *But see, In re Colyer*, 99 Wn.2d at 129, (stating that these statutory limitations on a guardian's power must be narrowly construed). When in doubt, a guardian may always petition the court for specific authority to consent to a particular treatment. This is a particularly good idea when there is disagreement among close family members.
28. *In re Hayes*, 93 Wn.2d 228, 238, 608 P.2d 635 (1980).
29. *See, e.g.*, WAC 388-97-055 (resident health care decision making); WAC 388-97-060 (informed consent); WAC 388-97-065 (advance directives); and WAC 388-97-07005 (notice of rights and services, including list of rights).
30. WAC 388-97-055(1).
31. WAC 388-97-055(3)(a-b).
32. WAC 388-97-065(3)(b).
33. WAC 388-97-055(6).
34. WAC 388-97-055(4)(b).
35. WAC 388-97-055(4)(c).
36. WAC 388-97-055(8)(a-b).
37. WAC 388-97-055(9)(b).
38. RCW 26.28.010.
39. RCW 7.70.065 (2).
40. RCW 26.16.125 (equal rights and responsibilities of parents).
41. RCW 7.70.050(4).

****NOTE: This manual was last updated in 2015. Some content may be out of date.****

42. Joint Commission, *Comprehensive Accreditation Manual for Hospitals: The Official Handbook*, March update, 2007.

Section 6: Physician Orders for Life Sustaining Treatment (POLST)

The goal of the Physician Orders for Life Sustaining Treatment (POLST) program is to effectively communicate the wishes of seriously ill patients to have or to limit life-sustaining medical treatment as they move from one care setting to another(1). There is a tremendous amount of emotion involved when it comes time to determine what type of care an individual wants ordered by his or her physician in preparation for possible life-threatening medical events. The Physician Orders for Life Sustaining Treatment (POLST) form is a tool that facilitates this decision process. The POLST form also ensures that a patient's end-of-life care decisions are made known to health care providers, family members, and emergency personnel. It is also helpful for initiating compassionate end-of-life discussions with patients and family members.

The materials following this overview of POLST are intended to assist facilities in implementing the POLST program and encouraging its use among staff and patients. Included in this section are:

- [list of POLST resources](#)
- [list of POLST contacts and speaker resources](#)
- [POLST form](#)
- [sample of DSHS approved policy and procedures for implementing the POLST form in nursing homes](#)(developed by St. Joseph Care Center) (PDF)
- [sample step-by-step procedures for nursing home intake of a patient with a POLST form](#) (developed by St. Joseph Care Center) (PDF)
- [sample hospital nursing procedures](#) (developed by Sacred Heart Medical Center) (PDF)
- [letter from DSHS recognizing right of legal surrogates to make informed consent decisions for residents](#)(December 14, 2000) (PDF)
- [letter from DSHS encouraging nursing home administrators to share POLST information with residents](#)(September 24, 2007) (PDF)

The key aspects of the POLST form are:

- A POLST form may be appropriate for anyone with a serious and/or life-limiting disease.
- The POLST form is portable, following the patient through all care settings, including home, emergency rooms, hospitals, and nursing homes.
- When completed, the POLST form is a physician order, treated as such.
- The POLST form is not an advance directive. It may complement an advance directive, but is a separate document.
- The form must contain signatures from **both** the patient and provider.

The POLST program originated in Oregon and has been used in Washington since 2000. The program developed from collaboration by providers and interested parties and the promotion of the use of

POLST has been a grassroots effort. In Washington State, the POLST form has replaced EMS-No CPR forms.

POLST is widely used and accepted for a number of reasons. The form promotes patient autonomy, clarifies treatment wishes, and facilitates appropriate treatment. Additionally, the form translates patient decisions into actual physician orders that are recognizable at an emergency site, emergency room, hospital, or long-term care facility such as a nursing home or hospice. The POLST form ensures that first responders can immediately ascertain a patient's wishes regarding medical treatment. The form travels with the individual through every care setting, gives standardized information, and reduces the need for repetitive end-of-life discussions. Importantly, POLST also offers both patient and physician comfort and security in knowing that the options and choices they discuss will be carried out no matter what the care setting.

POLST is appropriate for any adult patient over the age of 18 with a life-limiting medical condition, especially anyone who has chosen "Do Not Resuscitate" or "No Code Status" in response to a full cardiorespiratory arrest. The standard question a physician should ask of himself or herself when deciding to initiate a POLST form is: would it surprise me if this patient died in six months to a year? Physicians who foresee the possibility that a patient may not live through the year should recommend a POLST form be completed. This could be applicable to a patient with a serious medical condition, as well as an elderly patient.

The POLST form is not an advance directive and does not replace or mitigate the importance of advance directives. Though it may complement a living will or durable power of attorney for health care, it is a separate and distinct tool in end-of-life care. Living wills are limited in the amount of information they can provide. A durable power of attorney serves mainly to appoint a surrogate decision-maker for health care decisions in the event that the patient cannot give consent. A POLST form offers a more detailed record of decisions made while the individual or surrogate decision-maker has the very latest information about health concerns and options. The POLST form translates the black and white wishes expressed in advance directives into physician orders that better encompass the nuances of a specific situation.

POLST is a straightforward two-sided form (2). The front of the POLST form allows the person completing the form to "check the box" indicating types of care desired by the patient. Choices on the front of the form include: resuscitation, medical interventions, antibiotics, and artificially administered nutrition. There is also a section to summarize the goals of the treatment plan. While comfort care is always emphasized, the patient may choose aggressive or non-aggressive treatment options. The back of the form gives contact information, additional directions on the use of POLST, and a section for review of the POLST form. The form should be reviewed periodically and upon transfer, change in health status, or change in the patient's treatment preferences. If the POLST form is changed, void the old form and fill out a new one. A POLST form may be revoked at any time by a patient with capacity or by the surrogate decision-maker if the patient lacks capacity.

The POLST form may be presented to the patient and discussed by a member of the health care team including a nurse, social worker, or chaplain but must be reviewed with the patient and signed by a physician, nurse practitioner, or physician assistant. The form should be completed after discussion with the patient or legal surrogate decision-maker regarding the individual's preferences. The form is not operational unless signed by both the health care provider (physician, nurse practitioner, or physician

assistant) and patient or surrogate. Both signatures must be present for the patient to receive the end-of-life care indicated on the POLST form. Signatures may be faxed and attached to the form as an addendum or the entire form may be faxed back and forth in order to get a provider signature.

The ideal time to fill out a POLST is in a non-emergency setting. Discussion during a routine office visit allows the physician, patient, and family time to consider and discuss treatment options and implications. POLST forms may also be completed during inpatient treatment, prior to discharge, or upon admission to a hospice or long-term nursing facility.

The POLST form is two-sided and printed on bright green paper. The form may be photocopied and the paper color is not mandatory, but the bright green paper is encouraged as it promotes visibility and recognition in each care setting and facilitates its use and transfer with the individual. Emergency personnel are more likely to recognize the form in a home care setting if it is this standard color. The POLST form in this section is a standard example of the current form. Printing on cardstock makes the form more durable and visible, but may hamper faxing.

If the holder of a POLST form is in a health care facility, the form should be at the front of the clinical record obvious and easily recognizable. The original form travels with the patient when transferred or discharged, but a copy may be kept in the patient's record, depending on the policy of the institution. If the individual chooses to remain at or return home, ensure that the original POLST form is taken home with the person and suggest that it be posted in a highly visible place. Standard locations include the refrigerator door, the back of the bedroom door, the front of the medicine cabinet, or beside the individual's bed. Emergency personnel will look to these common, prominent locations upon entering.

The POLST form is used extensively in Washington State and is endorsed by several associations and state agencies. The form is endorsed by the Washington State Hospital Association, the Washington State Medical Association, and the Association of Washington Public Hospital Districts. The Washington State Department of Health (DOH) supports the POLST form and the Department of Social and Health Services (DSHS) allows the use of the POLST form in nursing homes.

RCW 43.70.480 directs the Department of Health (DOH) to adopt guidelines and protocols to train emergency medical personnel in responding to the site of an emergency to treat a patient who has indicated, in some written form, that he or she does not wish to receive futile emergency medical treatment. The statute further directs that these protocols be set forth in a "simple form" to be used statewide. DOH has adopted POLST to fulfill this statutory requirement. The department trains members of the Emergency Medical Services and Trauma System in how to use a POLST form should one be present at the scene of a medical emergency. DOH will authorize the use of the POLST form in any Washington State county.

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1. <http://www.ohsu.edu/polst> Accessed July 19, 2007.
 2. The POLST form is periodically reviewed and revised. Older versions are valid, but providers are encouraged to use the latest version.

Section 7: State and Federal Law on Organ Procurement

Washington state law governing organ procurement is encompassed in the revised Uniform Anatomical Gift Act. (1) Among other things, the Act delineates who may donate organs, who may receive a donated organ, and the obligations placed on hospitals and physicians to facilitate donations. Organ donation is generally referred to in the Act as an “anatomical gift”. The Act is concerned with increasing organ donation and reducing the ratio between available organs and individuals needing a transplant.

In addition to the revised Uniform Anatomical Gift Act, the Centers for Medicare and Medicaid Services (CMS) Conditions of Participation and the Joint Commission standards on organ procurement set out requirements hospitals must meet. The Medicare Conditions of Participation are comprehensive and require specific hospital procedures and protocol, including collaboration with organ and tissue procurement organizations. The Joint Commission standards closely conform to those set forth by CMS.

The revised Uniform Anatomical Gift Act, the Medicare Conditions of Participation, and Joint Commission standards are discussed below.

Relevant law and regulations are discussed in this section. At the end of this section is a list of resources, including a resource guide from the Department of Health and Human Services prepared to assist hospitals in complying with the law. This information provides program suggestions, a resource list of government agencies and advocacy organizations, and general information on organ procurement.

To summarize, the law on organ procurement for hospitals in Washington State requires:

- Any adult, emancipated minor, or minor aged 15½ or older may donate all or part of his or her body for transplantation, therapy, research, or education. Donations may be rescinded or revoked in some circumstances.
- Family consent is not needed if an adult has expressed the desire to be an organ or tissue donor upon death.
- Hospitals and medical personnel are required to ask any deceased individual’s next of kin, at or near the time of death, whether the deceased is an organ donor.
- Hospitals must enter into agreements or affiliations with organ procurement organizations to coordinate the procurement and use of anatomical gifts.

The information presented in this section outlines the legal obligations of hospitals that do not perform organ, tissue, or eye transplantations in their facilities. This information is not comprehensive for hospitals that have transplant centers or facilities.

The Revised Uniform Anatomical Gift Act

The revised Uniform Anatomical Gift Act (UAGA) is contained in RCW 68.64.010 through 68.64.903. The UAGA was revised in 2008 to generally comply with the federal revised Uniform Anatomical Gift Act. Uniformity among state laws was sought in order to facilitate speed and efficiency in donations and transplantations across state boundaries. In addition to increasing uniformity, the revised UAGA allows individuals as young as 15½ to donate, sets up new rules addressing decision-making by next of kin, and dictates a process hospitals and physicians must follow in the event of a conflict between an advance directive and a document addressing organ donation. The revised UAGA also allows the Department of

Licensing to transfer all information relating to organ and tissue donors to any Washington state organ procurement organization that intends to establish a statewide organ and tissue donor registry. (2)

Hospitals should be aware that under the new Act:

- Hospitals must enter into agreements or affiliations with at least one procurement organization to facilitate coordination of procurement and use of anatomical gifts. (3)
- Neither the physician who attends a decedent at death, nor the physician who determines time of death, may participate in procuring the decedent's organs. (4)
- Unless the individual expressed contrary intent, a hospital must take measures to ensure the medical suitability of an individual at or near death while a procurement organization examines the patient for suitability as a donor. (5)
- If there is a conflict between an advance directive and the measures necessary to ensure suitability to donate under the terms of an anatomical gift donation, measures must be taken to ensure the medical suitability of the prospective donor while the conflict is resolved. Measures may only be withheld if they are contraindicated by appropriate end-of-life care. (6)

Hospitals are still obligated to take specific steps to inquire about organ donation, document the inquiry, and designate a hospital representative to discuss organ donation with patients near death. While the revised UAGA no longer imposes these obligations on hospitals, they are still required by both CMS and the Joint Commission.

The following is an overview of the revised UAGA:

The Act defines an anatomical gift as “a donation of all or part of a human body to take effect after the donor's death for the purpose of transplantation, therapy, research, or education.” (7) While all four purposes are valid, if a donation is made for more than one purpose, transplantation or therapy is given priority over research or education. (8)

Who may donate

The donor may make an anatomical gift during his or her lifetime if the donor is an adult, an emancipated minor, or 15§ (the age at which a minor may apply for a driver's license). An individual other than the donor may make an anatomical gift if:

- the person is expressly authorized to make health care decisions on the donor's behalf via power of health care attorney or expressly authorized to make an anatomical gift by the donor.
- the person is the parent of an unemancipated minor donor (however, this donation expires once the donor is emancipated or reaches adulthood).
- the person is the donor's guardian. (9)

With the exception of unemancipated minors, once a donor has made an anatomical gift, all other persons are prohibited from making, amending, or revoking the gift. (10)

If a person has not documented a preference with respect to donation of organs or body parts, the statute allows other interested persons to consent to donation. Absent a deceased person's instructions not to donate, RCW 68.64.070 lists seven classes of persons authorized to consent to donation on behalf of the deceased person. Consent must be obtained in the following order of priority:

1. the agent of the decedent (holder of power of attorney for health care or expressly authorized to make an anatomical gift by a signed record;
 2. the spouse or state registered domestic partner of the decedent;
 3. the adult child of the decedent;
 4. the parents of the decedent;
 5. adult siblings of the decedent;
 6. adult grandchildren of the decedent;
 7. grandparents of the decedent;
 8. any person acting as the guardian of the person of the decedent at the time of death;
 9. any other person having authority under applicable law to dispose of the decedent's remains.
- (11)

If a member of a higher class is reasonably available to make a donation decision, individuals in lower classes may not make the decision. (12) Any anatomical gift made by an authorized person may be revoked or amended by any member of a prior class, orally or in writing. (13) However, revocation is only effective if the procurement organization, transplant hospital, physician, or technician knows of the revocation before an incision is made to remove the donated body part or before the transplant procedures have begun on the recipient. (14) Once these procedures have begun, any revocation is moot.

If there is more than one person in any of the above classes, any member may make the decision to donate all or part of the decedent's body, unless the person or the entity who will receive the organ knows that another member of the class objects. If so, the donation may only be made if by a majority of the members who are reasonably available. Reasonably available is defined as "able to be contacted by a procurement organization without undue effort" and willing and able to give timely consent. (15)

Instruments of donation

A donor may make an anatomical gift via a "document of gift", a will, or a communication addressed to one adult and one disinterested witness during a terminal illness or injury. A "document of gift" is "a donor card or other record used to make an anatomical gift. The term includes a statement or symbol on a driver's license, identification card, or donor registry." (16) Note that revocation, suspension, expiration, or cancellation of a driver's license or identification card does not void the donation.

An authorized person may make an anatomical gift for a decedent via a document of gift signed by the person or by oral communication contemporaneously recorded and signed. (17)

Refusal, revocation, and amendment of gift

A donor may, during his or her lifetime, amend or revoke an anatomical gift via a signed record or a later-executed document of gift. An authorized person (an agent, parent, or guardian) may revoke or amend a gift via a signed record witnessed by two adults, one of whom is a disinterested witness. (18)

An individual may also execute a refusal to donate. This may be done in the same manner as amendment or revocation, in a will, or any form of communication to two witnesses during a terminal injury or accident. (19) An individual's unrevoked refusal to donate bars any donation by any other persons.

A donor or authorized person may also revoke an anatomical gift by destroying or cancelling the document of the gift with the intent to revoke. (20)

Any donation made by an authorized person on behalf of a decedent may be amended or revoked by a person of a prior class. If multiple members of a class are reasonably available, the gift can be amended only if the majority of the available members agree. (21) Similarly, the gift can only be revoked if a majority of the available members agree or are equally divided. (22)

The revised UAGA makes it clear that, absent express action by the donor, organ donation should be encouraged and facilitated. Thus, under the Act, revocation by a donor of an anatomical gift is not a refusal and does not bar an authorized person from making an anatomical gift. (23) Refusal to donate by an individual other than the donor does not stop another authorized person from making a donation. (24) Absent an express, contrary indication, an anatomical gift of a specific body part is not a refusal to donate another part and does not limit donation of another part by the donor or another. (25) Similarly, absent an express, contrary indication, an anatomical gift made for a specific purpose (transplantation, therapy, research, or education) does not limit making a gift for another purpose.

An individual who acts in accordance with the UAGA, or attempts to do so in good faith, is not liable for the act in a civil action, criminal prosecution, or administrative proceeding. (26)

Advance Directives and Organ Donation

The revised Uniform Anatomical Gift Act specifically addresses the possibility of a conflict between an advance directive and measures necessary to ensure medical suitability for organ donation. If a prospective donor's advance directive or declaration and the terms of a potential anatomical gift are in conflict regarding the measures necessary to ensure medical suitability of a donated organ or body part, the donor's attending physician and donor (or agent or authorized person if donor is incapacitated) must confer to resolve the conflict. (27) Conflicts are to be resolved expeditiously. While the conflict exists, measures must be taken to ensure the medical suitability of the prospective donor while the conflict is resolved. Measures may only be withheld if they are contraindicated by appropriate end-of-life care. (28)

Nursing Homes and Organ Donation

Nursing homes are regulated under WAC 388-97-065, entitled Advance Directives, which refers specifically to organ and tissue donation. The term "advance directive" in the section specifically encompasses organ donation. This regulation is discussed in Section One of this manual and the text appears in Section Three.

Medicare and Medicaid Conditions of Participation on Organ Procurement

The Centers for Medicare and Medicaid Services (CMS) issued Conditions of Participation on organ procurement designed to increase organ donation. (29) The regulations impose several requirements a hospital must meet. They became effective August 21, 1998.

The CMS Conditions of Participation are the requirements hospitals must meet to participate in the Medicare and Medicaid programs. They are intended to protect patient health and safety and to assure that high quality care is provided.

These requirements apply to all Medicare and Medicaid participating hospitals including: short term, psychiatric, rehabilitation, long-term, children's, and alcohol-drug hospitals, whether or not they are accredited. This rule does not apply to Critical Access Hospitals (see Social Security Act, Section 1861(e)). However, the Conditions of Participation for Critical Access Hospitals include requirements for organ, tissue, and eye procurement that mirror the written protocols that hospitals must have. (30) The obligations regarding written protocols apply to both hospitals and Critical Access Hospitals, but the portion on organ transplantation responsibilities does not apply to Critical Access Hospitals.

The CMS organ procurement regulations codified in 42 C.F.R., Section 482, Conditions of Participation: organ, tissue, and eye procurement, require hospitals to:

- Have and implement written protocols that:
 - Establish an agreement with an organ procurement organization (OPO) under which the hospital will notify the OPO, in a timely manner, of every individual whose death is imminent or who has died in the hospital ? this step is taken prior to approaching the family to determine patient suitability. (31) Notification must be made for every individual who has died at the hospital, or whose death is imminent, regardless of medical suitability. The organ procurement organization will determine suitability after notification. (32) CMS interpretive guidelines direct that these written protocols must define "imminent death" and "timely notification," specify notification methods and triggers, and permit regular access to the hospital's death record information.
 - The OPO must be one designated by the Secretary of the Department of Health and Human Services.
 - The OPO may designate a third party to receive the notifications of patient death.
 - The OPO determines the patient's medical suitability for organ donation.
 - The OPO determines medical suitability for tissue and eye donation, absent an alternative arrangement by the hospital.
 - When death is imminent, the hospital must notify the OPO both before a potential donor is removed from a ventilator and while the potential donor's organs are still viable.
 - Establish an agreement with at least one tissue bank and at least one eye bank to cooperate in the retrieval, processing, preservation, storage, and distribution of tissues and eyes, as may be appropriate to assure that all usable tissue and eyes are obtained from potential donors. (33)
 - The agreement must not interfere with organ procurement.
 - The tissue bank and eye bank define "usable tissue" and "usable eyes."
 - Ensure, in collaboration with an OPO, that the family of each potential donor is informed of the options to donate organs, tissue, or eyes, or to decline to donate. (34) If possible, the OPO and hospital representatives should approach the family together.
 - The individual designated to approach family members must be either an organ procurement representative or a designated requestor.
 - A designated requestor is an individual who has completed a course offered or approved by the OPO and designated in conjunction with the tissue and eye bank community on how to approach families and request organ or tissue

- donation. The designated person may also be a representative of the organ procurement organization. (35)
- Encourage discretion and sensitivity with respect to the circumstances, views, and beliefs of the families of potential donors. (36)
 - Using discretion does not mean a judgment can be made by the hospitals that certain families should not be approached. Hospitals should approach all families with the belief that a donation is possible, treating family members with care and respect. The hospital staff's perception that a family's grief, race, ethnicity, religion, or socioeconomic background would prevent donation should never be used as a reason not to approach a family.
- Ensure that the hospital works cooperatively with the designated OPO and at least one tissue bank and one eye bank in educating staff on donation issues, reviewing death records to improve identification of potential donors, and maintain potential donors with necessary testing and ensure that placement of organs and tissues takes place. (37)
- Comply with organ transplantation responsibilities:
 - A hospital that performs transplants must be a member of the Organ Procurement and Transplantation Network (OPTN) and abide by its rules. (38)
 - The OPTN is established and operated under the Public Health Service Act. (39)
 - If a hospital performs any type of transplant, it must provide organ-transplant-related data, as requested by the OPTN, the Scientific Registry, and the organ procurement organization. (40)
 - The hospital must also supply this data to the Secretary of HHS when requested to do so.
 - The term "organ" in these standards means a human kidney, liver, heart, lung, or pancreas. (41)

When the CMS regulations were published, they referenced a study demonstrating that family members of a deceased individual are much more likely to consent to organ donation when the following three elements are in place at the time of request:

- First, family members must be given time to understand and accept their relative's death before the donation request is made.
- Second, consent rates are higher when the request is made by the OPO in conjunction with the hospital staff. In the study, either their requests were made at the same time, or the OPO made a formal request after the designated hospital staff mentioned organ donation.
- Third, the setting in which the request is made should be quiet and private, such as a conference room or family meeting room. (42)

The Joint Commission Accreditation

The Joint Commission's 2007 Comprehensive Accreditation Manual for Hospitals contains standards that are very similar to the CMS Conditions of Participation. Organ procurement is addressed in Leadership (LD) standard 3.110 and the companion elements of performance, which was newly amended in January of 2007. Any Joint Commission-accredited facility, including hospitals, outpatient clinics, and nursing homes, must adhere to the Joint Commission standards in order to retain accreditation.

The Joint Commission does not require hospitals to ask patients about their organ donation wishes unless required by law, regulation, organization policy or procedure, or by agreement with an Organ Procurement Organization. If organ donation is specified in a patient's advance directive or verbally expressed by the patient, the hospital should approach this wish as it would all other portions of an advance directive. This includes honoring the patient's wishes within the limits of the facility's capacity. (43) (See Section One for Joint Commission standards regarding advance directives.)

The following Joint Commission standards address organ procurement:

LD.3.110

Leaders implement policies and procedures developed with the medical staff's participation for procuring and donating organs and other tissues.

- Organ procurement policies and procedures apply to all potential organ donors.
- Hospitals must:
 - Have an agreement with an appropriate organ procurement organization (OPO) and follows its rules and regulations.
 - Have an agreement with at least one tissue bank and at least one eye bank (so long as the process does not interfere with organ procurement) to cooperate in retrieving, processing, preserving, storing, and distributing tissues and eyes.
 - Belong to the organ procurement and transplantation network (OPTN) and follow its rules and regulations if the hospital transplants organs.
 - Provide all organ transplant-related data upon request of the OPTN, the Scientific Registry, or the hospital's designated OPO.
- The hospital must have policies and procedures for organ and tissue procurement and donation, including the following elements:
 - the OPO with which the hospital is affiliated;
 - the OPO is notified of a patient who has died or whose death is imminent prior to the withdrawal of life-sustaining therapies, within the time jointly agreed upon by the hospital and OPO, and according to the triggers mutually agreed upon;
 - the OPO determines medical suitability for organ donation and, in the absence of alternative arrangements by the hospital, for tissue and eye donation;
 - procedures, mutually developed with the OPO, for notifying the family of each potential donor of the option to donate — or decline to donate — organs, tissues, or eyes;
 - written documentation by the hospital's designated requestor showing that a patient or family accepts or declines the opportunity to donate organs or tissues;
 - staff education includes training in the use of discretion and sensitivity to the circumstances, beliefs, and desires of the families of potential donors;the hospital

- maintains records of potential donors whose names have been sent to the OPO and tissue and eye banks; and
- the hospital works cooperatively with the OPO, tissue, and eye banks in order to:
 - review death records to improve identification of potential donors;
 - ensure the necessary testing and placement of potentially donated organs, tissues, and eyes takes place to maximize viability;
 - educate staff about donation issues; and
 - develop a donation policy that addresses opportunities for asystolic recovery, based on an organ potential for donation that is mutually agreeable by the OPO, hospital, and medical staff.

RI.2.80

The hospital addresses the wishes of the patient relating to end-of-life decisions.

- The hospital documents and honors the patient's wishes concerning organ donation within the limits of the law or hospital capacity.

HR.2.10

The hospital provides initial orientation.

Training should include:

- Hospital-wide policies and procedures (including safety and infection control) and relevant unit, setting, or program-specific policies and procedures.
- Specific job duties and responsibilities and service, setting, or program-specific job duties and responsibilities related to safety and infection control.
- Cultural diversity and sensitivity.
- Education about patient safety and ethical aspects of care, treatment, and services and the process used to address ethical issues.

HR.2.30

Ongoing education, including in-services, training, and other activities, maintains and improves competence.

Ongoing education must be documented and ought to:

- Increase staff knowledge of work-related issues, laws, regulations, and the needs of the patient population.
- Occur when job responsibilities or duties change.
- Emphasize specific job-related aspects of safety and infection prevention and control.

[Organ and Body Donation Resources](#)

1. In 2008, the Washington state legislature adopted the revised Uniform Anatomical Gift Act, issued by the National Conference of Commissioners on Uniform State Laws (NCCUSL) in 2006. Second Engrossed Substitute H.B. 1637, 60th Leg. Sess., Reg. Sess. (Wash. 2008).
2. RCW 68.64.200.
3. RCW 68.64.140.
4. RCW 68.64.120(9).
5. RCW 68.64.120(3).
6. RCW 68.64.180(2).
7. RCW 68.64.010(3).
8. RCW 68.64.100(4).
9. RCW 68.64.030.
10. RCW 68.64.070(1).
11. A hospital or physician may rely on the representations made by individuals regarding their status as a member of a class authorized to make donation decisions, unless the hospital or physician knows the representation is false. RCW 68.64.170.
12. RCW 68.64.080(3).
13. RCW 68.64.090(2).
14. RCW 68.64.090(3).
15. RCW 68.65.010(24).
16. RCW 68.64.010.
17. RCW 68.64.090(1).
18. RCW 68.64.050(1)(b).
19. RCW 68.64.060(1) & (2).
20. RCW 68.64.050(3).
21. RCW 68.64.090(2)(a).
22. RCW 68.64.090(2)(b).
23. RCW 68.64.070(2).
24. RCW 68.64.070(3).

25. RCW 68.64.070(5).
26. RCW 68.64.170(1).
27. RCW 68.64.180(2).
28. RCW 68.64.180(2).
29. The statutory authority for the Conditions of Participation for organ donation is derived in part from section 1138 of the Social Security Act, entitled “Hospital protocols for organ procurement and standards for organ procurement agencies.”
30. 42 C.F.R. § 485.643.
31. 42 C.F.R. § 482.45(a)(1) and 42 C.F.R. § 485.643(a).
32. CMS Interpretive Guidelines, State Operations Manual, Appendix A ? Survey Protocol, Regulations and Interpretive Guidelines for Hospitals, www.cms.hhs.gov/GuidanceForLawsAndRegulations/08_Hospitals.asp.
33. 42 C.F.R. § 482.45(a)(2) and 42 C.F.R. § 485.643(b).
34. 42 C.F.R. § 482.45(a)(3). Under 42 C.F.R. § 485.643(c) the individual designated by Critical Access Hospitals to approach families must be a designated requestor.
35. See the Medicare Conditions of Participation section for further information.
36. 42 C.F.R. § 482.45(a)(4) and 42 C.F.R. § 485.643(d).
37. 42 C.F.R. § 482.45(a)(5) and 42 C.F.R. § 485.643(e).
38. 42 C.F.R. § 482.45(b)(1).
39. 42 U.S.C. § 274.
40. 42 C.F.R. § 482.45(b)(3).
41. 42 C.F.R. § 482.45(b)(2).
42. Medicare and Medicaid Programs Hospital Conditions of Participation for Identification of Potential Organ, Tissue, and Eye Donors and Transplant Hospitals’ Provision of Transplant-Related Data, 63 Federal Register 33856 (June 22, 1998) (to be codified at 42 C.F.R. pt. 482).
43. The Joint Commission website http://www.jointcommission.org/AccreditationPrograms/Hospitals/Standards/09_FAQs/RI/Organ_Donation.htm, accessed August 30, 2007.

Resources

Resources for Providers

American Academy of Hospice and Palliative Medicine

4700 W Lake Avenue
Glenview, IL 60025

(847) 375-4712

www.aahpm.org

American Board of Hospice and Palliative Medicine

9200 Daleview Court
Silver Spring, MD 20901

(301) 439-8001

www.abhpm.org

American Hospice Foundation

2120 L Street NW, Suite 200
Washington, DC 20037

(800) 347-1413 FREE

www.americanhospice.org

Center for Practical Bioethics

Harzfeld Building
1111 Main Street, Suite 500
Kansas City, MO 64105-2116

(800) 344-3829 FREE

www.practicalbioethics.org

Center to Advance Palliative Care

1255 Fifth Avenue, Suite C-2
New York, NY 10029

(212) 201-2670

www.capc.org

Centers for Medicare and Medicaid Services

Conditions for Coverage and Conditions of Participation

www.cms.hhs.gov/CFCsAndCoPs/

Cross Cultural Health Care

270 S. Hanford Street, Suite 208
Seattle, WA 98134

(206) 860-0329

www.xculture.org

End of Life /

Palliative Education Resource Center

www.eperc.mcw.edu

National Hospice and Palliative Care Organization

1700 Diagonal Road, Suite 625
Alexandria, VA 22314

(703) 837-1500

www.nhpco.org

www.promotingexcellence.org

Ethics in Medicine

University of Washington School of Medicine

<http://depts.washington.edu/bioethx/topics/index.html>

BOOKS

Dying Well: The Prospect for Growth at the End of Life

Ira Byock. Riverhead Books, New York, 1997.

Managing Death in the ICU: The Transition from Cure to Comfort

J. Randall Curtis and Gordon D. Rubenfeld. Oxford University Press, Oxford, 2000.

Please see the resource pages at the end of sections [2](#), [6](#) and [7](#) of the End of Life Care Manual for resources specific to those sections.

Visit the [Resources for Patients](#) page.

Resources for Patients

American Association of Retired Persons

601 E Street NW
Washington, DC 20049

(888) 687-2277 FREE

www.aarp.org/families/end_life

Americans for Better Care of the Dying

1700 Diagonal Road, Suite 635
Alexandria, VA 22314

(703) 647-8505

www.abcd-caring.org/

Association of Washington Public Hospital Districts

300 Elliott Avenue West, Suite 300
Seattle, WA 98119

(206) 281-7211

http://www.awphd.org/Publications/resources_endoflife.aspx

Beth Israel Medical Center

First Avenue at 16th Street
New York, NY 10003

(877) 620-9999 FREE

www.stoppain.org

Caring Connections

(800) 658-8898 FREE

www.caringinfo.org

Compassion & Choices of Washington

PO Box 61369
Seattle, WA 98141

Elder Law Answers

535 Boylston Street, 8th Floor
Boston, MA 02116-3720

www.elderlawanswers.com

End of Life Consensus Coalition

Washington State Medical Association
2033 6th Avenue, Suite 1100
Seattle, WA 98121

www.wsma.org/patients/weolcc.html

Family Caregiver Alliance

180 Montgomery Street, Suite 11001
San Francisco, CA 94104

(800) 445-8106 FREE

www.caregiver.org

Growth House, Inc.

(415) 863-3045

www.growthhouse.org

Lawyer Referral Services

Washington State Bar Association
1325 4th Avenue, Suite 600
Seattle, WA 98101-2539

(800) 945-9722 FREE

www.wsba.org

Washington State Catholic Conference

710 9th Avenue
Seattle, WA 98104

(206) 301-0556

www.thewsscc.org

Washington State Medical Association

2033 6th Avenue, Suite 1100



Seattle, WA 98121

(877) 222-2816 FREE

www.candcofwa.org

**Dying Well: Defining Wellness
Through the End of Life**

www.dyingwell.org

(800) 552-0612 FREE

[http://www.wsma.org/patient_resources/
end-of-life.cfm](http://www.wsma.org/patient_resources/end-of-life.cfm)

Please see the resource pages at the end of sections [2](#), [6](#) and [7](#) of the End of Life Care Manual for resources specific to those sections.

Visit the [Resources for Providers](#) page.

Information for Patients and Families

If you are a patient or family member looking for resources to help in your medical decision-making, Honoring Choices Pacific Northwest is designed for you. Co-sponsored by the Washington State Hospital Association (WSHA) and Washington State Medical Association (WSMA), Honoring Choices has a vision that everyone in the state will receive medical care that honors their personal values and goals. Learn more at [Honoring Choices](#).